

# American Indian Health Disparities in the 21st Century



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Edited by

Cornelius M. Dyke and Donald K. Warne

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# CHAPTER 1

## AMERICAN INDIAN AND ALASKAN NATIVE HEALTHCARE DELIVERY

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### **Lessons from the COVID Pandemic**

The COVID pandemic is a microcosm of the health disparities affecting American Indian/Alaskan Native peoples. SARS-CoV-2 has hit poor, underserved, and vulnerable populations especially hard throughout the US, and persons of color are disproportionately affected. While data on disparities among AI/ANs is sparse, COVID-19 has struck AI/AN communities particularly hard. The incidence of COVID in AI/AN communities has been reported to be over three times the incidence affecting whites.<sup>1</sup> Additionally, the Navajo Nation has had more per capita cases and deaths than any US state. In New Mexico, where 9% of the population is American Indian, 75% of COVID deaths were American Indians, while this figure was 12% in Arizona despite American Indians only making up 4% of the population.

While the incidence of co-morbid conditions such as diabetes mellitus and chronic respiratory disease is known to be higher in AI/ANs and certainly contributes to the severity of disease in exposed patients, non-medical factors which affect health and well-being are especially relevant to the COVID pandemic. Crowded housing conditions, lack of running water, poor road conditions, and the need for shared vehicles, as well as a lack of access to hospitals and understaffed clinics, all contribute to the severe and disparate effect of COVID on AI/ANs. Even the lack of cellphone and internet access and the lack of access to reliable COVID data are problematic and contribute to the disparities seen in AI/ANs.<sup>2</sup> As vaccines become available, it will be critically important that AI/ANs and other vulnerable populations have adequate access to them. Indian Health

Service Director Rear Admiral Weahkee has stated that “the success of a COVID-19 vaccine program for tribes and urban Indian communities depends on the strong partnership between the federal government, tribes and urban leaders,”<sup>3</sup> highlighting the complex interactions between the federal government and the AI/AN people. From understanding the incidence, to treatment, to prevention, COVID is a prism which focuses and clarifies the disparities demonstrated in AI/AN healthcare, which has relevance to other diseases discussed elsewhere in this monograph.

## **Population and Demographics**

According to the 2010 US Census, 5.2 million people identified as American Indian and Alaskan Native (AI/AN), either alone or in combination with another race.<sup>4</sup> 2.9 million persons identified as AI/AN alone. In 2017, there were an estimated 5.7 million people classifying as AI/AN alone or in combination, comprising 1.7% of the total US population. The AI/AN population, either alone or in combination, grew rapidly between the 2000 and 2010 census, increasing by 39%. Most of the AI/AN population live in the West, with the South having the second highest proportion of AI/AN peoples. Having said that, New York, NY, and Los Angeles, CA, are the two population centers with the highest population of AI/ANs and Anchorage is the city with the largest proportion of AI/AN citizens. California, Oklahoma, Arizona, Texas, New York, New Mexico, Washington, North Carolina, Florida, and Michigan were the ten states with the largest AI/AN populations.

There are 573 federally recognized AI/AN tribes, and these tribes receive health and educational assistance through the Indian Health Service (IHS), a part of the US Department of Health and Human Services. A description of the Indian Health Service and its history is below. 22% of American Indian/Alaskan Natives live in an American Indian area such as a federal reservation or state designated AI area. The Navajo Nation and the Pine Ridge reservation are the reservations with the largest AI/AN populations. The Cherokee and Navajo are the two largest tribal groupings of AI/AN. 78% of AI/AN live outside of tribal areas, and it is estimated that 70% of AI/ANs live in urban areas. The IHS funds 41 urban Indian health organizations operating within these urban areas.

Insurance status and economic considerations are inexorably bound to individual healthcare and well-being. In 2017, 51% of AI/ANs had private health insurance coverage compared to 73% of non-Hispanic whites.<sup>5</sup> 43% of AI/AN relied on Medicaid and 15% had no health insurance, both dramatically higher than non-Hispanic whites. Reservation land is

predominantly rural with a total land mass of approximately 100 million acres, larger than ten states. The infrastructure on reservation land is inadequate: in 2016, 161,000 miles of roads qualified for federal funding assistance, and 75% of existing roads on reservation lands were unpaved.<sup>6</sup> Infrastructure needs have been cited as causal factors for health and education disparities, especially among children.

## **Obligations and Historical Perspective**

American Indians and Alaskan Natives have a unique relationship with the US government. Since the founding of this country, this relationship has been characterized by warfare, conflict, land seizure, forced assimilation and acculturation, and governmental mediation and resolution. The relationship of the US and AI/AN tribes has been one of government to government negotiation and contractual obligations.<sup>7</sup> Between 1778 and 1868, 367 treaties were ratified by the federal government, with these treaties being the “supreme law of the land”. Many treaty obligations arose out of land seizure and eminent domain claims and utilize phrases such as the “promise of all proper care and protection” in exchange for land and resources. This obligation was described by the first Supreme Court Chief Justice John Marshall in 1831 as a “trust relationship”, whereby seized lands and resources were exchanged for a legal administered financial obligation on behalf of the federal government to defend tribal treaty rights, lands, and resources, as well as a duty to provide health services and promote well-being. These treaties, which were signed between sovereign nations (tribal and federal), are the basis for the obligations owed by the federal government. They serve as contracts for the provision of health and well-being by the federal government to AI/AN peoples. Health services provided by Indian Health Service and federal government are not “free health care” but should rather be considered the first and largest prepaid health plan in history, paid for by the land and resources given up by tribal nations. In addition to these treaty rights, as American citizens, American Indians and Alaskan Natives are eligible to participate in all public, private, and state health programs available to the general public.

Four major legislative acts of Congress have been passed in the twentieth century which have shaped the healthcare provided to AI/ANs. The Snyder Act of 1921 allowed Congress the ability to appropriate federal funds “for relief of distress and conservation of health [...] and for the employment of [...] physicians” and is the basis for the current federal funding of the IHS. The IHS itself was created by the Transfer Act in 1954 under the administration of the Surgeon General and the US Public Health

Service. This Act also recognized tribal sovereignty and afforded tribal self-determination in health policy decision making. Perhaps the most significant piece of legislation shaping how AI/ANs are cared for today was the Indian Self-Determination and Education Assistance Act (ISDEAA) of 1975. The ISDEAA became the basis on which authorizing tribes could assume the management of the IHS programs and directed the Departments of Interior and Health and Human Services to enter into contracts with tribal authorities. This Act allowed for carry-over funding, third-party revenue, grant eligibility, and contract support costs through the “638 contract”, which is essentially a block grant to a specific tribe for the total IHS budget amount. More than half of the IHS budget is currently managed by tribes under the ISDEAA. In 1976, the Indian Health Care Improvement Act (IHCIA) was passed; this established the Urban Indian Health Programs (34 nationally) and allowed the IHS and tribal 638 programs to bill Medicare and Medicaid. Together, these legislative acts have created the “I/T/U” healthcare delivery system for AI/ANs that is used today (I for Indian, T for Tribal 638 program, and U for urban health centers). The IHCIA was permanently reauthorized in 2010 as part of the Affordable Care Act (ACA). Within that Act it is stated that “Congress declares that it is the policy of this Nation, in fulfillment of its special trust responsibilities and legal obligations to Indians to ensure the highest possible health status for Indians and urban Indians and to provide all resources necessary to effect that policy”. While granting Congress the authority to appropriate dollars to effect this policy, there is no guarantee they will appropriate the necessary resources to achieve this obligation.

The remainder of this monograph will address AI/AN health disparities in more detail in a disease-specific manner. Throughout the chapters, however, common themes will emerge: data on American Indian health is frequently sparse, disparities in American Indian health are apparent and severe, and societal and “non-medical” factors profoundly influence American Indian health. Causal factors are uniformly multifactorial and exist on the personal, societal, and healthcare delivery levels. While many of these factors are common in other at-risk populations, including rural communities and other racial groups, many of these are unique to the American Indian/Alaskan Native.

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## CHAPTER 2

# DISPARITIES OF INFECTIOUS DISEASES IN AMERICAN INDIANS

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### **Introduction**

Significant disparities are notable in American Indian/Alaskan Native (AI/AN) populations with regard to infectious diseases. These disparities exist for many reasons and are linked to social determinants of health, such as higher rates of unemployment, lower family income, decreased access to healthier foods and adequate nutrition, as well as individual determinants of health, such as unintentional injury, violence, obesity, diabetes, tobacco use, and substance use disorder.<sup>1</sup> These disparities not only reflect unmet health needs, but also inefficient use of health resources either due to a lack of availability or access or due to cultural and individual beliefs. These differences demand that strategies be developed to tackle not only the disparities in this population but also the determinants of health in high-risk regions and across all age groups.

American Indians are not included in the national health and nutrition survey (NHANES) which is conducted by the National Center for Health Statistics, Centers for Disease Control and Prevention (CDC). Most systematic data collection that is available for review is obtained from the Indian Health Service (IHS) which serves about 2.2 million people.<sup>2</sup> IHS is also the primary source for data on hospitalization rates for AI/ANs but, unfortunately, it underestimates these rates relative to other Americans because it cannot track all hospitalizations of AI/ANs in the population it serves.<sup>3</sup> Although the infectious disease hospitalization rates for AI/AN people have declined over time, they remain higher than the general US

population in the Southwest, Alaska, and Northern Plains regions. These infectious diseases hospitalizations account for approximately 22% of all AI/AN hospitalizations.<sup>4</sup> A study comparing hospitalization and avoidable hospitalization rates for a rural AI/AN population with those of non-Indians living in the same regions and using the same hospital system have shown that hospitalization and avoidable hospitalization rates were both higher for the AI/AN population.<sup>3</sup> This signifies that improved access to care may be a reasonable strategy to address some of the disparities encountered. In another study, infectious diseases diagnoses accounted for 19% of AI/AN hospitalizations compared with 12% of non-AI/AN hospitalizations. The study also reported that the average annual age-adjusted hospitalization rates were more than 3 times higher for the AI/AN population (2697/100,000) as compared to non-AI/AN persons (730/100,000).<sup>5</sup> The most common infectious disease leading to hospitalization among AI/AN population is a lower respiratory tract infection. In the subsequent sections, we will discuss health disparities affecting AI/ANs with regard to specific infectious disease conditions.

## **Vaccine Preventable Infectious Diseases (VP-IDs) in Children**

Of all infectious diseases related hospitalizations, lower respiratory tract infections (LRTIs) accounted for the largest proportion at 35% followed by skin and soft tissue infections (SSTIs) at 19% and infections of the kidney urinary tract and bladder at 11%.<sup>4</sup> In one study assessing the hospitalization of AI/AN children compared to other racial and ethnic groups using the 2012 Kids Inpatient Database (KID), AI/AN children were more likely to be admitted to hospital for a vaccine preventable infectious disease (VP-ID) compared to non-Hispanic White children.<sup>6</sup>

Influenza is a highly contagious respiratory tract infections that affects millions of Americans every year and results in hundreds of thousands of hospitalizations and an estimated 12,000 to 61,000 deaths annually.<sup>7</sup> Although different groups of people, like those more than 65 years of age, pregnant women, people with asthma, and young children, have been identified as being at an increased risk of complications from the influenza virus, AI/ANs are the only racial group in the US to be identified as having a higher risk for developing influenza-related complications. During each of the four influenza pandemics over the last century, AI/ANs suffered significantly higher rates of mortality compared to any other racial or ethnic group. These disparities in influenza-related complications and deaths are most glaring in the early stages of life: children younger than five years of

age are almost twice as much at risk compared to non-Hispanic White children. Given that these are potentially preventable deaths with vaccination, this is a significant disease burden that needs to be targeted to reduce overall death rates.<sup>8</sup>

Like influenza, Respiratory Syncytial Virus (RSV) is a well-known leading cause of LRTIs among infants and young children and responsible for large proportion of hospitalization among all US children but more so in the AI/AN population. The rate of bronchiolitis associated hospitalization is significantly greater in AI/AN infants as compared to that of general population (61.8 vs. 34.2 per 1000). This difference may be secondary to either an increased likelihood of severe RSV-associated disease or a decreased threshold for hospitalization among AI/AN infants with bronchiolitis. This reflects a heightened need for LRTI prevention programs including a RSV vaccine if and when it becomes available.<sup>9</sup> The lack of in-home water service is an example of a social determinant of health that impacts respiratory and gastrointestinal infections. The provision of a safe and adequate water supply would provide an opportunity to reduce health disparities by investing in the improvement of the sanitation infrastructure.<sup>10</sup>

Diarrhea and gastrointestinal infections are a common reason for hospitalization and outpatient clinic visits among all children. When comparing the data available from HIS registry and KID and National Ambulatory data over a five-year period from 2000–2004, Singleton et al. found that AI/AN infants had almost twice the rates of hospitalization (262.6 vs. 154.7 of 10,000) and significantly higher rates of outpatient clinic visits (2255.4 vs. 1647.9 of 10,000) for diarrhea and gastrointestinal illnesses compared to the general US infant population.<sup>11</sup> This again highlights the issue of vaccine preventable diseases, like rotavirus, causing a higher morbidity burden, as well as the importance of a safe water supply infrastructure.

### **Methicillin Resistant *Staphylococcus aureus* (MRSA) Infections**

AI/AN communities have had outbreaks of MRSA infections. In order to study the disease burden, Byrd and others studied data between 1996–1998 and 2003–2005 utilizing the IHS registry and compared the same to a nationwide inpatient sample. This analysis revealed that, even though the age adjusted rates of hospitalizations among AI/ANs (58.8 per 100,000 persons) were lower than that of the general US population (84.7 hospitalizations per 100,000 persons), the rate of MRSA-associated

hospitalizations increased significantly from 4.6 to 50.6 hospitalizations per 100,000 persons in the AI/AN population during the two study periods.<sup>12</sup> It also indicated that, during this time period, infection with MRSA became more common than Methicillin susceptible *Staphylococcus aureus*. As for the specific infections, skin and soft tissue infections accounted for a significant majority of these infections followed by diabetic-related infections, bone infections, urinary tract infections, sepsis, postoperative infections, pneumonias, implanted device related infections, and bacteremias.

## Tuberculosis

Tuberculosis is by far the most common infection in the human population, as it affects about a third of the world's population. Caused by *Mycobacterium tuberculosis*, TB is transmitted from person to person through airborne droplets. TB usually affects the lungs but can cause infections in other body systems as well including the lymph nodes, spine, brain, abdomen, and genitourinary tract. However, not everyone exposed to TB develops the disease. Two distinct TB syndromes exist: a latent TB infection (LTBI: where the bacteria remain quiescent in the lung tissues) and an active TB disease (where the bacteria lead to disease by invading tissues and organ systems). In LTBI, bacteria are not actively dividing and are thus not transmissible from one person to another.

According to latest available World Health Organization (WHO) data, about 10 million people worldwide developed active TB in 2017 and out of this figure 1.6 million people succumbed to the illness.<sup>13</sup> In the US, the incidence of TB has declined significantly over the past few decades, but it seems to have stabilized at about 2.8 cases/100,000 population.<sup>14</sup> According to the CDC, in 2015, 85% of TB cases occurred in racial and ethnic minorities. This points to an overwhelming health disparity which, once again, is the result of the complex interactions between individuals, communities, and social determinants of health.<sup>15</sup> Other contributing factors include an increased burden of diabetes and other chronic health conditions which increase the risk of the acquisition and development of TB disease.

Although most of the TB cases in the US occur in foreign born individuals who immigrate from areas of high TB burden, AI/ANs are disproportionately affected and have experienced the smallest decrease in TB case rates among any US born racial/ethnic groups.<sup>16</sup> The same study also found that, in 2002, out of the 15,075 TB cases reported in the US, 180 were reported in the AI/AN population leading to an incidence rate of 8.4/100,000, almost six times the rate of non-Hispanic Whites. Follow-up data has found that this overwhelming disparity continues to persist and has

also identified other risk factors, such as homelessness, higher rates of alcoholism, residence in counties with higher rates of poverty, and living without health insurance, that may be contributing to the increased incidence of TB. Reassuringly, the same study found that AI/ANs had the largest proportion of cases receiving directly observed therapy (DOT) for treatment of TB making them more likely than those in other racial/ethnic groups to receive total DOT. The treatment completion rates for AIs were similar compared to other racial groups. According to the latest data available from the CDC, the rates of TB in the AI/AN population are currently at 4.3 cases per 100,000 population and are similar to those observed in African American and Hispanic population. These compare with a lowest rate of 0.5/100,000 in non-Hispanic Whites and the highest rate of 20.0/100,000 in Native Hawaiians and other Pacific Islanders.<sup>17</sup>

TB outbreaks continue to occur among ethnic minorities however and the American Indian population is no exception. A recent example occurred in Grand Forks County, North Dakota in 2012, which led to the highest number of cases seen in a particular area in the past decade.<sup>18</sup> Outbreaks of TB in low incidence areas like North Dakota present unique challenges in disease prevention and control due to the lack of a prompt recognition of the disease due to its rare occurrence and the lack of local expertise in the management of active TB. These barriers can be overcome by enlisting the help of external resources and collaborating with local healthcare personnel with an extensive community knowledge to expedite the contact investigation and facilitate a proper follow up and treatment completion.<sup>19</sup>

## Hepatitis C

Hepatitis C Virus (HCV) infection is the most common blood borne infection in the US, which affects about 3.5 million people and causes an estimated 20,000 deaths per year due to liver failure or hepatocellular carcinoma.<sup>20</sup> The mode of spread is primarily through sharing contaminated needles to inject recreational drugs. Unlike Hepatitis B, most adults exposed to HCV go on to establish a chronic infectious state in the liver which may lead to the development of cirrhosis or hepatocellular carcinoma several years after exposure. HCV infection is mostly asymptomatic and therefore the current US Preventive Services Task Force (USPSTF) guidelines recommend screening the at-risk population and persons born between 1945–1965 utilizing a serological assay.<sup>21</sup> The rates of HCV infection have risen exponentially over the last few years due to the ongoing opioid epidemic. AI are disproportionately affected with the rate of new infections estimated at 2.9 cases/100,000 as compared to the rate of 0.5 cases/100,000

in African Americans and 1.2 cases/100,000 in non-Hispanic Whites.<sup>22</sup> Moreover, the mortality rate directly attributable to HCV is also significantly higher in the AI population compared to all other racial and ethnic groups.<sup>20</sup> According to the latest available CDC data from 2017, AIs have an HCV related mortality rate of 10.24 cases/100,000 population compared to rates of 7.03/100,000 cases in African Americans and 3.7/100,000 in non-Hispanic Whites.<sup>22</sup>

Despite the current screening recommendations from the USPSTF, the rates of detection of HCV infection remain low partly because risk-based screening is poorly informed due to provider misperceptions, the need for uncomfortable discussions, and the fear of retribution among patients. Although certain strategies, such as adding a reminder in electronic health record for clinical decision support and providing education, have been shown to increase the rates of testing and retention of care in HCV infected patients, USPSTF's move to switch from risk based screening for HCV to universal screening may be more effective.<sup>23</sup>

From a treatment standpoint, extremely safe and well tolerated oral co-formulated, direct-acting antiviral agents have eliminated the need for long term, sub-optimal, toxic, and inconvenient injection-based treatments since 2013. These newer medications are highly effective, as they provide cure rates in excess of 90% within eight to twelve weeks of treatment.<sup>24</sup> Reassuringly, these high cure rates are also seen in the AI population.<sup>25</sup> Unfortunately, uptake in real world settings has been severely hampered by the cost of these medications. Even though certain programs like the Department of Veterans Affairs health care system have allocated significant resources toward the treatment of HCV infections, poorly funded programs like the IHS are unable to cover these highly safe and effective, but expensive, treatments.<sup>26</sup> In order to cover various other health services, these under-funded programs are forced to impose artificial and fallacious barriers to medication access which significantly and negatively affect the AI population. For example, some insurance plans mandate a period of sobriety from drug and alcohol use before providing coverage for the treatment of an HCV infection. This leads to an exponential number of new cases of HCV infection as untreated patients continue to share contaminated needles, which further fuels the ongoing epidemic. Denial of treatment coverage based on ongoing alcohol use is also unfortunate as this specific subgroup of patients is more likely to go on to develop cirrhosis due to a "double-hit" to the liver from toxic effects of alcohol and the HCV infection.<sup>27,28</sup> Finally, many of the same insurance plans mandate a referral to a specialist to treat the HCV infection even though real world data indicate that cure rates tend to be higher when HCV infected patients are

treated by their primary care providers.<sup>29</sup> This may be related to the decreased need for multiple redundant appointments, the expense, and the inconvenience of traveling long distances while missing work and child rearing responsibilities to visit with another provider especially in sparsely populated regions. In order to address some of these concerns, a multi-disciplinary approach to treating patients with an HCV infection has been adopted in our clinic. This involves an initial visit with an HCV specialist, completing the requisite lab work and imaging procedures, electronic or phone call follow up of patients to ensure approval of medication coverage, counseling towards adherence, and timely testing for treatment tolerance, response, and ultimately cure. With this approach, we have been able to treat all patients who were able to start HCV treatment, including 40% of those who never returned for a follow up visit after the initial consultation (unpublished data).

If we are to realize the vision of making HCV infections a rare disease by 2030, we must advocate for our patients so we can provide the already available, highly safe, and effective treatment to our most vulnerable patient populations, including AIs.<sup>30</sup> It will take a concerted effort from health care workers, politicians, advocacy groups, drug manufacturers, and health insurance corporations to make this possible.

## **Sexually Transmitted Infections including Human Immunodeficiency Virus**

Sexually transmitted infections (STIs) are a major health concern in the US. Surveillance is very important to facilitate effective screening to identify and treat infected patients to prevent long-term health complications, such as infertility, and transmission. According to the annual *Sexually Transmitted Disease Surveillance Report* released by the CDC, the combined cases of syphilis, gonorrhea, and chlamydia have significantly increased in the US in 2018. Primary and secondary syphilis cases have increased 14% and, most concerning, include a 40% increase in syphilis cases among newborns. Gonorrhea cases have reached an all-time high of 580,000 cases while 1.7 million cases of chlamydia have been reported to the CDC in 2018, about two thirds of which are 15–24 years of age.<sup>31</sup>

With the nationwide increase in the incidence of STIs, even more concerning is the disproportionate rates among American Indians/Alaska natives (AI/ANs). In 2017, there were an estimated 5.6 million people who were classified as AI/AN, which was about 1.7% of the total US population.<sup>32</sup> Compared to most races, rates of STIs are higher among AI/ANs.<sup>33</sup> Data from the National Survey of Family Growth between 2006–

2010 showed that, compared to non-Hispanic Whites, AI/AN women were less likely to use birth control services but more likely to use services for STIs and human immunodeficiency virus (HIV) infections.<sup>34</sup> In 2015, the total rate of chlamydia infections for all IHS areas was 1.4 times higher than the overall US rate (an IHS rate of 693.6 per 100,000 population compared to the US rate of 478.8 cases per 100,000 population). Females had higher chlamydia rates than males in all IHS areas and the female to male AI/AN ratio was also higher compared to US rates. A similar trend can be seen with gonorrheal infections with the overall IHS gonorrhea rate being 1.5 times higher than US rates (IHS rate: 184.7; US rate: 123.9 cases per 100,000 population). During 2011–2015, the AI/AN primary and secondary syphilis rate was consistently lower than the US total rate, with the exception of 2014 when the AI/AN rate surpassed the US total rate. Despite this, AI/ANs had the fourth-highest primary and secondary syphilis rate in 2015.<sup>35</sup>

The rates of HIV infection in 2016 among AI/ANs were the fourth highest among racial groups in the US, behind African Americans, Hispanics/Latinos, and persons of multiple races.<sup>36</sup> From 2012–2016, there was a 34% increase in overall HIV diagnoses among AI/AN and up to a 58% increase specifically among gay and bisexual men.<sup>37</sup> Data analyzed by the CDC from the Medical Monitoring Project (MMP) showed that, from 2011–2015, a total of 64% of AI/AN HIV patients achieved sustained viral suppression while 76% achieved viral suppression within the past 12 months, which is below the national HIV prevention goal of 80%, but comparable to or better than some other racial/ethnic groups. Social and community factors are important when discussing STIs: about half of patients had incomes at or below the poverty limit, 27% had symptoms of depression, 78% reported internalized HIV-related stigma, and 20% reported binge drinking in the past 30 days.<sup>38</sup> These data highlight the sociodemographic and behavioral barriers that AI/AN patients with a HIV infection face when attempting to achieve viral suppression and improve health outcomes.

## **Other Notifiable Infectious Diseases Including COVID-19**

When data from the National Notifiable Diseases Surveillance System (NNDSS) from 2007–2011 were analyzed, 12 out of 22 diseases with >70% race information recorded had higher rates for AI/AN compared to Whites.<sup>39</sup> Though rare with only 112 cases, hantavirus pulmonary syndrome had the highest discrepancy with a tenfold increase in incidence in AIs compared to Whites. Tularemia (7.7x) and spotted fever rickettsiosis (4.2x) are also much more prevalent in AIs. Lower rates of infection in AIs were observed

with varicella, acute hepatitis A, acute hepatitis B, meningococcal infections, and pertussis, suggesting there would be a benefit from immunization programs. However, it must be acknowledged that surveillance data such as these are often limited by the quality, accuracy, and completion of racial information.

## **Emerging Infectious Diseases**

It is clear from the above discussion that AI/ANs are especially vulnerable to illnesses caused by known infectious agents. However, this discussion would be incomplete without sounding a word of warning about infectious agents that are currently unknown but nevertheless will lead to local or widespread epidemics. The same co-morbid conditions and social determinants of health that impart an increased susceptibility to and lead to an increased risk of complications from other infectious diseases will also be expected to lead to worse outcomes with emerging and re-emerging infectious diseases. This concern was validated by an epidemiological study of Rocky Mountain Spotted Fever which reported a 4-fold increased risk of disease burden and mortality among AI/ANs compared to Whites.<sup>40</sup>

At the time of writing this chapter, the world is still dealing with its latest pandemic: Coronavirus Infectious Disease 2019 (COVID-19), which is caused by the novel coronavirus SARS-CoV-2. The scale of this pandemic has been unprecedented, and one must go back a century to identify an infectious disease outbreak that led to such a large cluster of infections and related mortality on a global scale within such a short period of time. After it was first identified as the causative agent of a cluster of severe respiratory illness in Wuhan, China, in December 2019, SARS-CoV-2 quickly spread all over the world leading to 166 million infections and 3.4 million deaths by May 2021.<sup>41</sup> As impressive as these numbers may appear, they likely reflect a significant underestimation given the inability of overwhelmed healthcare systems to keep up with both case and death counts.

As this pandemic was growing exponentially and firmly establishing itself in various countries, states, and communities, local hospitals and public health resources were quickly overwhelmed and unprecedented measures for containment had to be initiated in the form of total or partial lockdowns. However, it quickly became clear that social distancing, one of the basic strategies in the fight against COVID-19, was also a privilege which was not equitably distributed throughout various sections of society. Racial minorities with the highest risk of complications from COVID-19 infection due to underlying health conditions and poor access to healthcare were unable to isolate and protect themselves by working remotely from

home or by taking time off work. These vulnerable populations frequently rely on public transportation due to not having their own vehicle. When forced to stay home due to infection or exposure, this frequently led to the loss of employment and associated health insurance.

Not unexpectedly, the pandemic disproportionately affected racial minorities including AI/ANs. According to the CDC, during the initial few months of the pandemic, the incidence of COVID-19 among AI/AN population was about 3.5 times that of Whites.<sup>42</sup> This higher incidence subsequently translated into higher mortality. According to data from the COVID tracking project at The Atlantic, the AI/AN population had 172 deaths per 100,000 people compared to 124 among Whites.<sup>43</sup>

Signs of hope, however, are emerging. The COVID pandemic as well as societal events have fostered discussions of racial health disparities in both mainstream media and medical literature. Several editorials not only pointed out the racial differences in the incidence and mortality related to COVID-19,<sup>44,45</sup> but also highlighted the racial disproportionality that existed among the participants enrolled in clinical trials to assess the efficacy and safety of treatments for COVID-19.<sup>46</sup> This led to an intentional effort to diversify the demographic makeup of the COVID-19 vaccine trials.<sup>47</sup> Once a highly effective vaccine became available, American Indians responded rapidly and positively leading not only to early access but also high vaccination rates.<sup>48</sup> This led to unparalleled and unprecedented success with the Navajo Nation going from one of the worst COVID-19 case rates to the first territory in the US to report zero cases and zero deaths in a 24 hour period on April 18, 2021.<sup>49</sup> This success highlights how focused efforts can produce highly desirable results.

## Conclusion

Disparities in incidence occur in a large number of infectious disease conditions among AI/ANs compared to other racial/ethnic groups and demand that strategies be developed to not only tackle the disparities in this population but also high-risk regions and age groups. These disparities not only reflect unmet health needs, but also the inefficient use of health resources either due to a lack of availability or access or due to cultural and individual beliefs. While the etiology of these disparities is multifactorial, major factors include several social determinants of health like higher rates of unemployment, lower family income, decreased access to healthier foods, and a higher level of social risks like unintentional injury, violence, obesity, diabetes, tobacco use, and substance use disorders. Awareness of such differences would lead to more focused and culturally responsive

interventions and public health programs to improve the well-being of the American Indian population.

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## CHAPTER 3

### CANCER DISPARITIES IN AMERICAN INDIANS

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The day before Loren McCabe's college graduation in 2013, his mother Victoria learned that her colon cancer had spread. She did not tell him until after the ceremony that she had decided to discontinue her treatment. Victoria, a former primary school teacher remembered for her enthusiasm in helping others, died nine months later.<sup>1</sup> In the months and years leading up to his graduation, Loren worked three jobs to support his family as he pursued a degree in landscape architecture. His younger sister had become their mother's primary caregiver as her condition gradually worsened. Loren's family lived in the Navajo Nation, where treatment options were limited. Victoria's treatment required traveling at least an hour each week from the family home in Ganado, Arizona, to Gallup, New Mexico. Occasionally they would have to complete the three-hour drive to Albuquerque, New Mexico. Occasionally, Victoria needed these treatments twice a week. McCabe remembers well the many stresses of traveling so far, so often: the constant stops for bathroom breaks, and the many days and nights spent away from their home and community. He remembers his mother telling him, "I hate doing this."<sup>1</sup>

Loren and his family were familiar with the challenges and demands of colon cancer. His great-grandmother was diagnosed too late to pursue treatment, and his grandfather chose to forego treatment because the long hours of driving would have taken him away from the Navajo Nation's four sacred mountains where he felt protected. Loren's family members had no choice but to travel long distances to treat their cancer, if it was diagnosed early enough for treatment to be an option.

Travel difficulties are an example of the disparities and the realities of cancer care for many American Indians living on reservations across the US. According to statistics compiled by the Navajo Epidemiology Center between 2005 and 2013, Navajos are seven times more likely to die from

gallbladder cancer, four times more likely to die from stomach cancer, and about twice as likely to die from kidney and liver cancer than non-Hispanic whites. They show lower rates of prostate, lung, and breast cancer.<sup>11</sup>

This chapter discusses the disparities found across the cancer continuum (from pre-diagnosis to death) affecting American Indian populations in the US. The National Cancer Institute lists the following parameters by which disparities may be reported.<sup>2</sup>

- Incidence (new cases)
- Prevalence (all existing cases)
- Mortality (deaths)
- Morbidity (cancer-related health complications)
- Survivorship, including quality of life after cancer treatment
- Burden of cancer or related health conditions
- Screening rates
- Stage at diagnosis

Disparities across the cancer continuum differ by both geographic region and primary cancer site. In order to begin addressing such complexities, the data presented in this chapter are generally specified according to those geographic regions delineated by the Regional Offices of the Indian Health Service (IHS). The IHS, a federal agency within the Department of Health and Human Services, is responsible for providing federal health services to approximately 2.6 million American Indians and Alaskan Natives belonging to 573 federally recognized tribes in 37 states.<sup>3</sup> The IHS oversees twelve Regional Offices, each supporting a distinct geographic region of the US.<sup>33</sup>

Understanding and studying cancer disparities affecting American Indians populations as a whole is complicated. Among the over 500 federally recognized tribes in the US, there is a substantial variation in the percentage of native ancestry required for tribal membership and, therefore, for eligibility in the IHS.<sup>4</sup> There are still tribes living across the US who are not recognized at the federal level at all.<sup>5</sup>

In a historical context of broken treaties and broken promises, there is also an issue of trust, which includes issues of respect for the data collected and preventing its misuse. Dr. Shobha Srinivasan, PhD is a Health Disparities Research Coordinator in the Division of Cancer Control and Population Sciences (DCCPS), which is an extramural division of the National Cancer Institute (NCI). Dr. Srinivasan explains:

*There's [...] the question of who ultimately owns the data and how the data will be used and published. The issue of data ownership is an issue of*

*sovereignty for the tribes, because in the past some researchers have used the data for something other than the purpose of the original study without the tribes' knowledge. [...] Because of this history, tribes now take very seriously the review of protocols for a study. They want to be true partners in studies, and they require that the information be given back to their communities in a way that is easily understood and explained, so that they can use the information to improve the health of the people in their communities.*<sup>6</sup>

## **Disparities Across the Cancer Continuum**

Much of the data on disparities across the cancer continuum in American Indian versus White populations is provided by the Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute (NCI). SEER Registries across the US collect patient data, including demographics, primary tumor site, tumor morphology, and stage at diagnosis, as well as data on treatments and follow-up. These registries cover almost 34.6% of the US population, which includes 31.9% of Whites, 30.0% of African Americans, 44.0% of Hispanics, 49.3% of American Indians and Alaska Natives, 57.5% of Asians, and 68.5% of Hawaiian/Pacific Islanders.<sup>6</sup> Much of the data provided by the SEER Program on American Indian/Alaskan Native (AI/AN) populations is typically based on the Contract Health Service Delivery Area (CHSDA) counties. These counties, who have been determined by the IHS, are geographic areas where contracted health services are made available to members of an identified American Indian community who reside in the area.<sup>7</sup>

The Seer Program publishes collected data in an annual report known as the SEER Cancer Statistics Review (CSR). The data, including cancer incidence, mortality, survival, prevalence, and lifetime risk statistics, are widely used by researchers, clinicians, public health officials, policymakers, and various community groups.<sup>7</sup> The data provided here include statistics from 1975 to 2016, which is the most recent year available from the SEER Program.<sup>9</sup>

From 2007 to 2016, the overall cancer incidence declined in the US.<sup>9</sup> The rate of decline varied by race, with American Indian/Alaska Natives (AI/AN) populations showing the least decline in cancer incidence with a -0.8 annual percentage change (APC). White populations showed a decline of -1.3 APC, while Black populations showed -1.7 APC. The largest declines in cancer incidence were observed in prostate and lung cancers in both AI/AN and White populations. AI/AN populations did not show significant declines in cancer incidence in any of the 13 other top cancer sites during this period. There were significant declines, however, in the

incidence rates of colorectal cancers, urinary and bladder cancers, non-Hodgkin's lymphoma, leukemia, and brain and other nervous system cancers in White populations during the same time interval.

When analyzed by sex and race, the incidence of cancers of the stomach declined among White males but showed no significant change among AI/AN males. Cancers of all sites declined significantly for White females, but no significant decline was seen in AI/AN females. By site, there were significant declines in lung cancers, colorectal cancers, NHL, ovarian cancers, urinary bladder cancers, and cervical cancers in White females. Only ovarian cancers showed a significant decline in AI/AN females.<sup>9</sup>

Some cancers have shown an increase in incidence. Thyroid cancers have increased significantly in AI/ANs as well as in White populations. Melanomas and cancers of the liver and the intrahepatic bile duct have increased significantly in White populations. The increase in liver and biliary cancers in AI/AN populations was not significant in this population. Data for melanomas in AI/AN populations are not available.

Cancer death rates have declined in the US by 1.5 APC from 2007 to 2016, though the rate of decline varies by race. The decline is lower in AI/AN populations (-1.3 APC), higher in White populations (-1.4 APC), and highest in Black populations (-2.1 APC).<sup>9</sup>

There have been significant declines in death rates for lung and bronchial cancers, renal and renal pelvic cancers, and leukemias in AI/AN and White populations between 2007 and 2016. The significant decline in death rates for colorectal cancer, prostate cancer, and NHL that was observed in the overall US population and White populations, however, was not observed in AI/AN populations. Similarly, White women noticed a significant death rate decline in breast and ovarian cancers, but no such significant decline was observed in AI/AN women. Death rates for colorectal cancers and cervical cancers showed a significant decline in AI/AN women.<sup>9</sup> Death rates for cancers of the liver and biliary ducts increased in the overall US population, as well as in White and AI/AN populations.

When considering all sites, overall cancer death rates in AI/AN populations are lower than in White populations (176.3 per 100,000 and 193 per 100,000, respectively). Within each CHSDA area, cancer death rates from 1999 to 2009 varied significantly by region for AI/ANs and minimally for Whites. Among AI/AN men, death rates for all cancer sites combined ranged from 163.8 in the Southwest to 338.1 in the Northern Plains. The lowest rate for any CHSDA area among White men was 207.1 in the Southwest, and the highest was 231.7 in the East. Among AI/AN women, the overall death rate for all cancer sites combined ranged from the lowest